

# HFEA Executive Licence Panel Meeting

5 October 2011

Finsbury Tower, 103 – 105 Bunhill Row, London, EC1Y 8HF

## Minutes – Item 4

### **Centre 0044 - (Centre For Reproductive and Genetic Health) – Variation of Licence to include HLA tissue typing in a specified patient couple with a child with Diamond Blackfan Anaemia (OMIM # 105650)**

|   |   |
|---|---|
| Members of the Panel:<br>Peter Thompson, Director of Strategy & Information (Chair)<br>Mark Bennett, Director of Finance & Facilities<br>Juliet Tizzard – Head of Policy and Communications | Committee Secretary:<br>Joanne McAlpine |
|---|---|

Declarations of Interest: members of the Panel declared that they had no conflicts of interest in relation to this item.

#### **The Panel also had before it:**

- HFEA Protocol for the Conduct of Meetings of Executive Licensing Panel
- 8th edition of the HFEA Code of Practice
- Human Fertilisation and Embryology Act 1990 (as amended)
- Decision trees for granting and renewing licences and considering requests to vary a licence (including the PGD decision tree)
- Guidance for members of Authority and Committees on the handling of conflicts of interest approved by the Authority on 21 January 2009.
- Guidance on periods for which new or renewed licences should be granted
- Standing Orders and Instrument of Delegation
- Indicative Sanctions Guidance
- HFEA Direction 0008 (where relevant), and any other relevant Directions issued by the Authority
- Guide to Licensing
- Compliance and Enforcement Policy
- Policy on Publication of Authority and Committee Papers

## **Consideration of Application**

1. The Panel noted the papers for this item consisted of an executive summary, a redacted application form, and a redacted letter from the clinician treating the affected child.
2. The Panel noted that Diamond Blackfan Anaemia had already been licensed by the HFEA for use in PGD and was considered to meet the statutory tests set out in the HFE Act.
3. The Panel noted that embryo testing for HLA typing to provide a bone marrow/stem cell match for a sibling suffering from a serious medical condition, is a lawful defined purpose for embryo testing, as specified at HF&E Act (1990) as amended, Schedule 2, para 1ZA (1) (d), and qualified by HF&E Act (1990) as amended, Schedule 2, para 1ZA (4).
4. The Panel noted that the patient couple have an eight year old daughter with Diamond Blackfan Anaemia. It appears that this is the sporadic form of the condition rather than the inherited one, though this diagnosis may reflect the fact that it pre dates genetic analysis. The patient couple wish to undergo IVF treatment with PGD to conceive a child who will be a tissue match for the child with Diamond Blackfan Anaemia.
5. The Panel noted the letter from the clinician treating the affected child, and noted that he/she is in support of the application and has provided appropriate detail about the severity of the condition and medical prognosis of the affected child.
6. The Panel noted the degree of suffering experienced by the affected child, involving regular blood transfusions, and chelation therapy.
8. The Panel noted that the Inspectorate recommended the variation of the centre's licence, to allow HLA for Diamond Blackfan Anaemia for the specified patient couple in the application.

## **Decision**

9. The Panel referred to its decision tree. The Panel noted that the purpose of the application did not include research. The Panel noted that stages 16d (i-v), which sets out the factors that need to be addressed when considering pre-implantation tissue typing, had been demonstrated and met.
10. The Panel noted that the letter from the treating clinician demonstrated the high degree of suffering associated with the condition and the lack of viable alternative treatment options. Accordingly, the Panel agreed that it had sufficient information and that it was satisfied that HLA tissue typing was appropriate for the patient concerned.

11. The Panel were satisfied that that those seeking treatment and their families will have proper access to counselling about the implications of the procedure.
12. The Panel agreed to vary the centre's licence to include HLA tissue typing for the named patients specified in the application, for a child suffering from Diamond Blackfan Anaemia.

Signed:   
Peter Thompson (Chair)

Date: 18/10/11.

